

Witness Name: KARIN PAPPENHEIM

Statement No.: WITN4504009

Exhibits: None

Dated: 21 May 2021

## INFECTED BLOOD INQUIRY

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### WRITTEN STATEMENT OF KARIN PAPPENHEIM

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I provide this statement in response to the request under Rule 9 of the Inquiry Rules 2006 dated 10 May 2021.

I, Karin Pappenheim, will say as follows: -

#### **Section 1: Introduction**

*Question 1: Please set out your name, address, date of birth and professional qualifications.*

1. My name is Karin Pappenheim of [GRO-C], London [GRO-C]. I was born on [GRO-C] 1954. My professional qualifications are set out in my CV attached at **WITN4504002**.

*Question 2: Please set out the positions you have held at the Haemophilia Society, and any other relevant organisations, and your role and responsibilities in these positions.*

2. I was the CEO of the Haemophilia Society from 30 March 1998 to April 2004.

*Question 3: Please set out your membership, past or present, of any committees or groups relevant to the Inquiry's Terms of Reference which can be found on the Inquiry's website at [www.infectedbloodinquiry.org.uk](http://www.infectedbloodinquiry.org.uk).*

3. As employee of the Society, in my capacity as CEO, I attended board meetings, committee meetings, and external meetings as required in performing my role. See my detailed witness statement.

## **Section 2: Responses to criticism**

### **Criticism by witness W3988**

4. At page 47, paragraph 2 of her witness statement, Witness W3988 states that the South Wales Haemophilia Group voiced concerns that the Haemophilia Society was not being proactive in campaigning for a HIV/hepatitis C public inquiry, specifically at an open meeting held on 10 September 1999 at the University Hospital of Wales which you attended. Please comment on this, including answers to the following:
5. I note that on page 47 para 2 of her statement, the witness refers to concerns raised by the South Wales Haemophilia Group about the Haemophilia's Society not being proactive in campaigning for a HIV/HCV public enquiry. The witness refers to an open meeting which I attended with Chris Hodgson, chair of the Society, on 10 September 1999. I cannot recall the detail of what was said at that meeting, and do not have a record of the meeting. It is possible that the Society may hold minutes of the meeting which could be obtained by the inquiry team.
6. To provide context for that meeting, I refer to section 8 of my first witness statement dated 14 May 2021 [WITN4504001] which covers the HCV campaign, and paragraph 125 which mentions the campaign review by board/CEO on 27 November 1999. Please note the date of that review meeting, which occurred in the two months subsequent to the open meeting in South Wales. I also cite documents **HSOC0016864** (Hepatitis Campaign future directions 25 September 1998) and **HSOC0009365** HAEMOPHILIA Society Day of Action for Hepatitis C victims 22 July 1998.
7. The latter document illustrates the Society's approach to the campaign when I first joined in 1998, at which time the main focus was on urging the government to respond to hepatitis C infection with financial recompense. However, in response to the criticism of the witness, I would draw attention to the fact that the press release and briefing are fully inclusive of the whole haemophilia community – those infected with HCV alone and those coinfecting with HIV and HCV. The document clearly states the impact of HIV infection on the whole

community: 1200 people infected with HIV and 4,800 with HCV. At that point, the focus of the campaign was raising awareness of the impact of HCV, and specifically the need for financial recompense. This was rejected by Government and so by autumn 1999, the time at which the open meeting in Wales took place, the Society had already begun a review of the campaign as shown in the 25 September 1998 document. That document clearly includes the public inquiry (see page 3 para 4) in proposed changes to the scope of the campaign.

*a. How did you respond to these concerns at the time?*

8. I understand that the witness felt that the Society was not campaigning hard enough for the public inquiry. However, as stated above, from autumn 1998 onwards the Society had already been expanding the campaign to include the public inquiry, and prior to that we had never failed to draw attention in our campaigns to the impact of both HIV and HCV on the community. It is possible that we were not able to communicate that clearly enough to members present at the meeting on 10 September 1999.

*b. What was your position on campaigning for a public inquiry in response to the HIV/Hepatitis C infections from infected blood and blood products?*

9. I cite the report written by me, which clearly proposes the public inquiry as a campaign objective: **HSOC0016864** (Hepatitis Campaign future directions 25 September 1998). I would also draw attention to the clear definition of the campaign aims in the Minutes of the Trustee Board meeting 11 September 2000 (see para 125 to 127 in my first witness statement dated 14 May 2021 [**WITN4504001**]) which clearly includes the public inquiry in the four aims, which were set out as follows:
- To persuade government to provide financial assistance to meet the needs of all people with haemophilia and related bleeding disorders affected by HCV
  - To press for the best treatment and care for people with haemophilia and related bleeding disorders infected with HCV
  - To persuade government to hold a full public inquiry into contaminated blood products
  - To ensure recombinant is available for all throughout the UK regardless of age of viral status
10. I note that this date is one year after the meeting in South Wales, which shows that the Society did listen and respond.

c. Do you consider that the Haemophilia Society was sufficient in their campaigning efforts for a public inquiry? If not, please explain why you consider that it was not sufficient.

11. Yes, I do believe that the Society campaigned hard for the public inquiry. Detail of our campaigning efforts is set out fully in my first witness statement dated 14 May 2021 [WITN4504001]. I would draw attention to the fact that the Society continued to campaign for a public inquiry after I left in 2004, and that persuading Government to set up and fund a public inquiry is not easy.

**Section 3: Other issues**

12. There are no other issues I wish to raise.

**Statement of Truth**

I believe that the facts stated in this witness statement are true.

Signed

GRO-C

Dated

21 May 2021